

Supporting those affected by Paget's Disease of Bone, funding research and raising awareness

ANNIVERSARY EDITION



YEARS

Plus

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George found it difficult to walk or stand

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Chair's message

Welcome to the 50th Anniversary edition of the Paget's News. As well as our usual features, we have a special feature on the Scientific Symposium and patient information meeting that was held at The Lowry in April of this year, to mark the 50th Anniversary of the Association. To mark this milestone, we have launched a new strategy for the next five years which is featured on pages 16-18. We have set ourselves five objectives; the first is to increase our reach to support people with Paget's disease. We plan to do this by launching our new website in the autumn and making more use of social media to support people in the UK and across the world. The second objective is to work to increase awareness of the disease. We will do this through various routes but most notably by working with other members of the medical profession who are not specialists in Paget's disease. Objective three is to promote early diagnosis and to ensure that people with Paget's disease can access high-quality medical care. An important part of the strategy will be to increase the number of Paget's Association Centres of Excellence (PACE) and in fact, four new centres were established this year, in Cambridge, Leicester, Stafford and London as detailed on pages 10-12. We are planning a further call for PACE centres later this year. The fourth aim is to continue to support research into Paget's disease, to improve understanding of the disease and improve outcomes for patients. The fifth aim is to continue to ensure that the Association has high standards of governance



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and to meet this aim we plan to establish the Paget's Association as a Charitable Incorporated Organisation within the next two years. The Trustees look forward to working with our members and wider society to meet these aims over the next five years.

Turning to the 50th Anniversary celebrations, we had a fantastic two days at The Lowry. The International Symposium on Paget's disease went very well and was supported by researchers from all over the world. The patient information event was also well received by all those present. For the evening gala event we were delighted to have the company of our Patron Sir Henry Paget who gave a short speech and handed out various

awards, including a special award to our Honorary President Graham Russell, in recognition of his research into bisphosphonates and to Dr Zoe Paskins from Keele and Dr Faiz Rahman from Leicester who have been awarded PACE centre status. The evening was rounded off by a live performance from our Patron Recardo Patrick who was brilliant. It was a night to remember. Full details on pages 20-25. I am also delighted to report that our £50,000 fundraising target was reached, with £50,982 donated to date. Thanks to everyone who contributed to this magnificent achievement! On the research front we focus on two papers recently published on Paget's disease; one about a patient who was incidentally discovered to have Paget's through a scan he had while being investigated as a potential kidney donor for his daughter. This is increasingly common and can lead to Paget's being detected before the disease becomes too advanced. The second paper from Quebec highlights decreasing severity of Paget's disease in recent years which is of course good news for those affected. This finding has now been found in many countries across the world, but the reasons are as yet, unclear.

I always like to read the personal experience stories and the one by George Samouel was no exception. George thinks Paget's disease may have been triggered by an injury early in life and there are previous reports of people getting the disease in bones that have been subject to trauma. It was rather disturbing that George initially didn't get investigated for hip pain later in life, but eventually

the diagnosis was made in 2012 because of a high ALP level. After having hip replacement surgery, the condition wasn't treated but eventually the high ALP levels responded to pamidronate but not to zoledronic acid. This is a bit unusual but as George says everyone is different! I am sure you will join me in wishing George all the best for the future! Although I wasn't aware of any research projects that he could help with currently, who knows what will happen in the future?

In closing I was sorry to hear that Doreen Scott, a longstanding supporter of the Association had passed away in April of this year. As highlighted in the tribute article by Diana Wilkinson, Doreen was quite badly affected by the disease but always had a positive outlook and never hesitated to help others affected by it. It's also good to hear that she gained a lot from being a member of the Association and made friends from people from all over the world through our Paget's Support Network.

I very much hope you enjoy reading this edition of the magazine as much as we did preparing it. It has been a hectic, but very rewarding year so far!

Keep safe and stay well.

Stuart Ralston

Chair, Paget's Association

The Paget's Association

Charity registration number: 266071

The Paget's Association is a charity in the United Kingdom, which focuses solely on Paget's Disease of Bone. Also known as The National Association for the Relief of Paget's Disease (NARPD), the charity was founded in 1973 by the late Mrs Ann Stansfield MBE.

In addition to providing information, support and guidance to all who require it, the Paget's Association raises awareness, and funds quality research.

Membership

Membership of the Paget's Association provides support and information in several ways. All members receive a Paget's Information Pack on joining, as well as our Paget's News magazine.

What is Paget's Disease of Bone?

Throughout life, normal bone is renewed and repaired through a process called bone remodelling. In Paget's disease, bone remodelling is accelerated and disorganised, leading to the formation of bone that has an abnormal structure.

Paget's disease may affect only one bone or several, and the affected bone is often enlarged and misshapen. It can be painful, and complications, such as fractures, can occur.

A more detailed explanation can be found on the Association's website and in our booklet '*Paget's Disease – The Facts*'.

Our website

There is a wealth of information regarding Paget's disease on our website.

www.paget.org.uk

Paget's Awareness Day

International Paget's Disease Awareness Day takes place annually on 11 January.

Contact us

The team at the Paget's Association would be more than happy to hear from you. Please get in touch!

Telephone

For all enquiries telephone:
0161 799 4646

Email

All general and membership enquiries:
membership@paget.org.uk

Postal address

You can write to us at the following address:

The Paget's Association,
Jactin House, 24 Hood Street,
Ancoats, Manchester, M4 6WX

Paget's Helpline

Our Paget's Helpline is available to anyone who requires support or has questions regarding Paget's disease. You can contact the Helpline by email, telephone (during office hours) or by writing to us at the address above.

■ Email: **helpline@paget.org.uk**

■ Telephone: **0161 799 4646**

■ Mobile: **07713 568197**

Chair of the Association

Professor Stuart Ralston
Email: **chair@paget.org.uk**

Connect with us on



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Paget's Association's Raffle

For clarity, the 200 Club will now be referred to as the Paget's Association's Raffle. Don't miss out on your chance of winning a prize in this monthly draw. By purchasing a number in our raffle you directly contribute to our charity and our mission to help those in need. Compared to other forms of lotteries or competitions, charity raffles like this generally have better odds of winning. We have a limit that we will never sell more than 200 tickets. Anyone over 18 can join and by encouraging friends, family and colleagues to join, you increase the funds raised and also raise awareness of Paget's disease.



Join today!

Remember, every ticket purchased brings you one step closer to winning a prize while supporting a cause you care about. For details and to join the Paget's Association's Raffle, please request a form by emailing membership@paget.org.uk or by telephoning **0161 766 4646**.



★★★★★ The lucky winners! ★★★★★

April

1st Prize £100

Ticket no. 169

*Janet Dixon
Lincolnshire*

2nd Prize £50

Ticket no. 185

*Christine Cratchley
London*

May

1st Prize £100

Ticket no. 6

*Shelagh Fletcher
Liverpool*

2nd Prize £50

Ticket no. 135

*Maureen Jones
Liverpool*

June Double prize draw

1st Prize £200

Ticket no. 195

*Norma Reid
Glasgow*

2nd Prize £100

Ticket no. 144

*Kathleen Ford
Hertfordshire*

Personal Experience

George Samouel wanted to tell his story to help others and remind us that everyone experiences Paget's disease differently.

Paget's disease is different in everyone

Nobody has been able to say when I developed Paget's disease. I realise that there are many unknowns about the causes but if one of the ways it can start is due to trauma, I can pinpoint it exactly to one evening in the middle of July 1968. I was riding my bike at about 9.30 pm when, coming off the kerb, I was run over by a young lad on a motor scooter. At the time I was concussed as I had hit my head. I was taken to hospital where I stayed under observation for several days. I had hit my left hip on the edge of the kerb and it was bleeding and bruised. This was not a priority at the time, however, I still have the scar.

As I got older I used to suffer what I thought was backache or sciatica, as my father suffered with this condition. During my 20s and 30s I used to play a lot of football and, if I had a problem, I would run it off, thinking that exercise would cure it. The pain would go and come back every so often.

It was not until about 20 years ago that the pain became very problematic. I would see my doctor and be sent to physiotherapy. This had short term benefits as the pain always came back. At this time I was living in Peterborough and one of the physiotherapists realised that there was a problem with my

left hip. He arranged for me to see a hip specialist at Peterborough Hospital. The specialist was not happy to see me and said I was too young to have a new hip. This was in 2005. At the time I was 49 years old. No further tests or investigations were considered. For one of my appointments I saw a locum GP who suggested that I start taking statins. This was one of my worst decisions ever as my left side developed severe spasms lasting several months. This was due to the Paget's. I found it difficult to walk, stand or put pressure on my leg and in the end I accepted that I had to live with this condition and try to work around it. When changing gear in the car I had to move my left leg with my hand.

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I found it difficult to walk, stand or put pressure on my leg
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In 2012 I moved to Bedford. I registered with a new doctors' practice and went through the process of tests and suchlike when you have a new doctor. Eventually one of the doctors suggested that I see a rheumatologist at Bedford Hospital. I had investigations, including blood tests, where my alkaline phosphatase (ALP) levels were found to be extremely high. The GP who saw me said that she

recognised my symptoms as her father was diagnosed with the same symptoms due to Paget's. I was given my first infusion of pamidronate and an appointment to see a hip specialist in Bedford. I was also put on amitriptyline to help ease the nerve pain.

Following several appointments, I was referred to the Royal National Orthopaedic Hospital (RNOH) in Stanmore. I was told that my Paget's disease was not rare but uncommon. The consultants found that my left femur had bowed making my leg one inch shorter and the leg had also twisted. I had 10% movement in my leg and walking was a real problem. Paget's was also found in the vertebrae at the base of my spine.

Hip replacement

I eventually had a total hip replacement in July 2015. My life changed as the pain went and I was walking. It was not until I went to the RNOH that I realised I was lucky compared to some people. However, not long after my operation, the doctors who had initially seen me left the GP practice and I was seeing new doctors who did not seem to understand my symptoms. My ALP levels were not monitored and I started having problems walking.

I moved to West Sussex in May 2021. Just before I had my yearly blood test at Bedford Hospital. A few weeks after my move I had a phone call from a doctor at my old

practice to tell me that I had severe fibrosis and should urgently see a doctor. After signing up with a new GP I had to go through the process of new tests and investigations. I am not really sure if my new practice had treated someone with Paget's before and I was eventually referred to a rheumatologist. When I finally got to speak to the consultant, after being told I was not a priority, I was given an infusion of zoledronate, which had no effect. After more phone calls and appointments, I was given an infusion of pamidronate, which did bring my ALP levels down. I am hoping for regular monitoring of my blood levels and will follow this up.

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My life changed as the pain went

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What has actually happened to my leg is that the hip is okay but there is (and always has been) muscle wastage. Also, due to the bowing of the leg, the knee does not sit right and this has led to arthritis and damage to the knee. I have been told there is nothing that can be done to help me. Being someone who wants to continue leading as normal life as possible, I will not be having any further surgery as I prefer other ways to manage the pain and having an operation does not guarantee a cure for my problems. In fact, I have met several people who have had knee operations and are now in a worse state. Following my findings on the internet, I am going to try to build up the strength in my left leg by use of weights, walking and any other thing that comes to light that I feel can help me.

Finding relief

I have researched many websites in respect of Paget's and try to identify things that might relate to me. I went back to taking amitriptyline but it had little effect so then tried gabapentin. Unfortunately, this also had little effect. I now have an appointment to see a pain consultant and have met a fantastic physiotherapist at my local hospital who encouraged me to look at alternative methods of getting more movement to my leg. I started doing stretching exercises which has given me more leg movement and I now have started playing, albeit very slowly, walking football.

I am also going to see someone from orthotics with a view to looking at my leg as it is shorter and I cannot open the knee properly. In addition, I am seeing someone from audiology, as it is clear that my hearing has been affected. However, there is a yearlong waiting list.

Paget's disease is different in everybody and it is clear that there is no cure. Therefore, taking responsibility for your treatment is important. There are many websites and a lot of information available which can help you manage this condition and maintain a programme of exercise. Keeping active is important. I enjoy DIY and

I love to climb on ladders, but now I know my limitations and how far I can go. Now part-time, I've been teaching for 25 years. I enjoy also reading and travelling. I am unable to do many activities as I worry about breaking a bone.

When I moved to East Sussex in 2021 I could put little pressure on my left leg and used to fall over and trip continuously. The NHS has been brilliant as they have allowed me to walk again and take control of my life. I have no intention of spending the rest of my life in a wheelchair.

I have been in touch with Dr Claire Clarkin, a researcher in Southampton, and Chair of the Association, Professor Stuart Ralston. I asked Stuart about involvement in any research, but he told me there is none relevant to me at present. Claire is researching blood vessels and Paget's disease and this seems to ring true with me. I will be keeping in contact with both of them.



George

What's your story?

We are grateful to George for sharing his story. If you would like to share your experience of Paget's disease, to help support others, please get in touch by emailing diana.wilkinson@paget.org.uk or by telephoning **0161 799 4646**. You will be given as much support as you need to write it down.

Stafford Information Event

27 October 2023

10.30 am to 3.00 pm

Our next Paget's Information Event is taking place at The Moat House, Stafford, a beautiful Grade II listed manor house hotel in the Staffordshire countryside. The venue has easy access from the M6 and is just 4 miles from Stafford train station (around 12 minutes in a taxi).

Bring your questions to this free event on 27 October 2023. Refreshments will be available at 10.30 am and the talks will commence at 11.15 am. Both refreshments and lunch will be provided free of charge.

Please see the full programme below.



The Moat House, Stafford

Reserve your place

You are welcome to bring someone with you but places must be booked in advance. You can book on our website, by completing and returning the form on the next page, by telephoning **0161 799 4646**, or by sending an email to membership@paget.org.uk

Paget's Information Event

Friday 27 October 2023

10.30 am – 3.00 pm

Acton Suite, The Moat House

Lower Penkrige Road, Acton Trussell, Stafford, ST17 0RJ

Refreshments and registration

Welcome

Chair: Professor Stuart Ralston

What is Paget's disease?

Dr Faiz Rahman

Trustee, Paget's Association & Consultant, Leicester

Diagnosis, present and future

Professor Stuart Ralston

Chair, Paget's Association, Consultant & Researcher, Edinburgh

Treatment

Dr Zoe Paskins

Consultant, Stoke-on-Trent, & Researcher, Keele University

Support for all

Mrs Diana Wilkinson

Specialist Paget's Nurse, Paget's Association

Physiotherapy

Mr Will Gregor

Consultant Physiotherapist, Salford

Pain in Paget's

Miss Kathryn Berg

Data Manager, Edinburgh

Pros and cons of joint replacement for people with Paget's

Mr Geraint Thomas

Consultant Surgeon, Oswestry & Senior Lecturer, Keele University

A final opportunity for questions

Professor Stuart Ralston

New Centres of Excellence



In this the Association's 50th year we were pleased to provide four UK centres with a badge of excellence.

As the only UK charity dedicated to Paget's disease, the Association is keen to improve patient access to appropriate specialist care. The Paget's Association Centre of Excellence award scheme recognises hospital and university departments which demonstrate expertise in both the clinical management of Paget's disease and research into the condition.

For the Paget's Association's 50th Anniversary, we are delighted to

announce that four centres were successful in their application for Centre of Excellence status. These are in London, Leicester, Cambridge and Stoke on Trent.

At an international conference in April, organised by the European Calcified Tissue Society and the Bone Research Society, our Chair Professor Stuart Ralston presented plaques to Dr Gavin Clunie from Cambridge and Professor Duncan Bassett from London.

Soon afterwards, at the Association's 50th Anniversary Gala Evening, Patron of the Paget's Association Sir Henry Paget expressed the importance of ensuring that people affected by Paget's disease can access high-quality care and presented plaques to Dr Faiz Rahman from Leicester and Dr Zoe Paskins from Stoke on Trent.

These four awards add to our growing list of UK Centres of Excellence.

Stoke on Trent

**Midlands Metabolic Bone Centre
Midlands Partnership NHS Foundation Trust
Haywood Hospital
High Lane Burslem
Stoke on Trent
ST6 7AG**

On behalf of the team at the Midlands Metabolic Bone Centre in Stoke on Trent, Dr Zoe Paskins received a Centre of Excellence plaque from Sir Henry Paget. Dr Paskins said, 'I'm delighted that the work of our fantastic multi-disciplinary bone team has been recognised with this award. It's a real privilege to receive this award and we look forward



Dr Zoe Paskins (right) receiving the award from Sir Henry Paget (left)

to working more closely with the Paget's Association to improve the

quality of care and support for people with Paget's disease.'

Cambridge

Metabolic Bone Unit, Addenbrooke's Hospital Hills Road, Cambridge CB2 0QQ

The Metabolic Bone Unit at Addenbrooke's Hospital, Cambridge was awarded Centre of Excellence status and Dr Gavin Clunie received a plaque from Professor Stuart Ralston. The unit has a long history of expertise in caring for people with Metabolic Bone Disorders including Paget's disease. Professor Juliet Compston, Dr Johnathan Reeve and Professor Ken Poole are notable clinicians, with global recognition for their pioneering research, who have worked at Cambridge over recent years. Dr Adrian Crisp also worked in the unit and was one of a number of people who reported on the benefit of pamidronate treatment for Paget's in the 1980s and early '90s. Clinical work is now led by Dr Gavin Clunie and staff who, through their rheumatology background, provide holistic care for people, not only who have Paget's disease, but also other musculoskeletal conditions that impinge their quality of life. The unit works closely with colleagues in Edinburgh on Paget's research.



Professor Stuart Ralston (right) presents the plaque to Dr Gavin Clunie (left)

Leicester

The Metabolic Bone Disorders Clinic Department of Metabolic Disease and Chemical Pathology University of Leicester Hospitals Leicester Royal Infirmary Infirmary Square Leicester LE1 5WW

Dr Faiz Rahman, Consultant in Metabolic Medicine and Clinical Biochemistry, together with Dr Prashanth Patel, Associate Professor (Hon) run the Metabolic Bone service at the University Hospitals of Leicester. This clinic caters for all types of metabolic bone diseases and has been actively participating in research activities related to Paget's disease. The clinic was established around 1985 by Dr SJ Iqbal. Initially it also catered for a paediatric age group but now only reviews adult



Sir Henry Paget (left) presenting Dr Faiz Rahman (right) with the plaque

patients. The service has expanded considerably and has clinics in Leicester Royal Infirmary and Leicester General Hospital. There is a dedicated day case investigation unit every Thursday at Leicester General Hospital for infusions and dynamic function tests. Other services involved in looking after patients with Paget's disease are all

available within the Trust, such as musculoskeletal radiology, orthopaedics, ENT, and special investigations including isotope bone scans and bone turnover markers. At the 50th Anniversary celebrations of the Paget's Association, Dr Rahman received the Centre of Excellence award on behalf of the team.

London

**The Endocrine Bone Unit
Imperial College Healthcare NHS Trust, St Mary's Hospital
1st Floor Mint Wing, Praed Street, London W2 1NY**

Professor Duncan Bassett was in Liverpool to receive a Centre of Excellence plaque from Professor Stuart Ralston. This has been awarded to the team at the Endocrine Bone Unit, Imperial College Healthcare NHS Trust, London. Clinical Lead Dr Alexander Comninos commented, 'The Endocrine Bone Unit is delighted to be selected as a new Paget's Association Centre of Excellence. We have four consultants in the team (Dr Comninos, Professor Bassett, Dr Cox and Dr Behary) and we care for a large number of people living with Paget's disease in London. We look forward to working with the Paget's Association to continually improve the care we offer as well as our understanding of this important disease.'



Professor Duncan Bassett receives the plaque from Professor Stuart Ralston on behalf of the team in London

Award-winning centres

The Paget's Association's Centre of Excellence award has been increasing awareness of the condition since 2015. It is anticipated that additional centres will be identified in the future. Information about all the centres can be found on our website and a full list is available from the Association's office.



A wet day for the London Marathon

On behalf of the Paget's Association, we want to thank our runners who took part in the TCS London Marathon on Sunday 23 April 2023. Their fantastic efforts raised awareness and funds to support the Paget's Association so that we can continue to help and support anyone affected by the disease.

One of the runners raising funds for the Association was Professor Fernando Gianfrancesco, a Senior Researcher at the Institute of Genetics and Biophysics of the National Research Council of Italy and Professor of Molecular Biotechnology at the University of Campania in Naples. He said, 'I completed the London Marathon in just over four and a half hours (4:33:16). The weather was bad. It was raining from start to finish but I had a lot of fun. The people were amazing and I think this marathon is one of the best in the world.'

Enter the TCS London Marathon 2024

With the excitement of this year's London Marathon over, it's time to ask who might be interested in taking on this world-famous challenge on 21 April 2024. Many people apply for a place in the TCS London Marathon by means of the public ballot. This is an entry for a place along with thousands of others and then winners are chosen at random in a draw. For the many who are unsuccessful in the draw an application can be made for a charity place. The Paget's Association has a limited number of

charity places and so we are seeking runners who would like to apply.

All successful applicants are required to pay a £50 non-refundable registration fee and raise a minimum of £1,500 in sponsorship. If you, or someone you know, is interested in taking part, please contact the Paget's Association to register your interest by emailing membership@paget.org.uk or telephoning **0161 799 4646**. An application form is also available on our website.



Professor Fernando Gianfrancesco taking on the iconic course



Please note our new address

**The Paget's Association
Jactin House
24 Hood Street
Ancoats
Manchester
M4 6WX**

No change to our telephone number
0161 799 4646



Important news for members

We would like to bring to your attention an important update regarding our Paget's News magazine. After careful consideration, the Trustees have decided to make a change to our current magazine schedule. Starting next year, the number of magazines published annually will be reduced from four to three.

This decision was made based on several factors including the need to optimise our resources, market trends and operational considerations. While we understand that some of you may have grown accustomed to receiving four magazines each year, we believe this adjustment will ultimately benefit the charity and our members. We will continue to produce content that is relevant, informative, and engaging. By focusing on fewer issues, we aim to deliver a more enriching and impactful reading experience.



We encourage you to share any concerns or suggestions you may have regarding this decision. We are committed to continuously improving and adapting to meet the evolving needs of our members and the wider community. Please feel free to reach out to us with any questions or comments you may have. We appreciate your understanding and ongoing support as we strive to provide the best possible experience for you all.

Annual General Meeting

The Annual General Meeting (AGM) of the Paget's Association will take place at 10.00 am on 27 October 2023, at The Moat House Stafford.

We encourage all members of the Association to join either in person or remotely using Zoom.

Please see the AGM information enclosed with this magazine.

AGM

A new strategy

For the Paget's Association's 50th Anniversary year, we have launched a new dynamic strategy for the next 5 years. The charity has a proud history of supporting those affected by Paget's disease, funding and encouraging research into the condition and raising awareness. We will build on this with a modern approach and with flexibility built in, enabling us to progress and adapt.

The Trustees and employees here at the Paget's Association are optimistic for the future and determined to make a positive difference to those who need our help. Are you ready to take this journey with us?



Chair of the Board of Trustees, Professor Stuart Ralston





The Paget's Association's Strategy 2023-2028

1

Continue to increase our reach to support more people affected by Paget's disease, their families, and carers

2

Increase awareness and understanding of Paget's disease among health professionals and the public

3

Promote early diagnosis and holistic care

4

Support Research into Paget's disease

5

Ensure continued good governance

Objective

1 Continue to increase our reach to support more people affected by Paget's disease, their families, and carers

Rationale

For 50 years the Paget's Association's support services have been a lifeline for those affected by Paget's disease, their families and those who care for them. Acknowledging that people seek information through different channels, we will further enhance our digital presence. In this way, we will be able to support more people to obtain the professional care that they need, as well as a good quality of life.

How we will increase our reach

- As we continue to be the trusted source of information on Paget's disease, we will lead the narrative and challenge myths around the condition.
- Through new investments in external partnerships, we will optimise our use of digital platforms, such as Facebook, to engage with more people who need our help – this will be enhanced by the launch of a new, dynamic and accessible website.
- We will increase our reach both in the UK and internationally through support services, which bring people together to share experiences, learn from each other and find support, i.e. Virtual Paget's Support Groups and face-to-face Paget's Information Events.
- We will continue to provide easily accessible support through

our Paget's Nurse Helpline and by providing evidence-based information in different formats.

- Through initiatives, such as our Focus Group, we will ensure the views of those affected by Paget's disease and their families are heard and considered.
- Review of membership options.

Objective

2 Increase awareness and understanding of Paget's disease among health professionals and the public

Rationale

Lack of awareness must be overcome to prevent unnecessary pain and suffering in those affected by Paget's disease. The Association must significantly increase awareness and address the apparent lack of understanding among health professionals. To ensure individuals seek help early there also needs to be an increased awareness among the general public.

How we will increase awareness and understanding

- We will continue to work with healthcare professionals to ensure our resources are accessible, relevant and helpful to them.
- We will develop new initiatives including digital campaigns and target information where it is most needed.
- The Association will highlight Paget's disease and the Paget's Association within relevant disciplines including orthopaedics and radiology.

- We will seek Paget's Ambassadors, who will raise awareness among healthcare professionals and researchers.
- We will continue discussions with the Association's Focus Group, which consists of those affected by Paget's and also relatives of those with the condition.
- International initiatives and partnerships will increase awareness and understanding overseas.
- International Paget's Awareness Day will intensify our awareness message globally.

Objective

3 Promote early diagnosis and holistic care

Rationale

Paget's disease is underdiagnosed. When a diagnosis is made, it can often be after several years of symptoms. In addition, it is often misdiagnosed, sometimes as cancer. We want to ensure that those affected by Paget's disease are diagnosed early and have access to appropriate specialist care.

How early diagnosis and holistic care will be promoted

- To facilitate access to specialist care across the UK, we will extend the Paget's Association Centre of Excellence scheme, identifying further hospitals where excellence in the care of those with Paget's disease is being achieved.

- We will seek to lessen missed opportunities for earlier diagnosis and intervention through education, guidance and support for healthcare professionals.
- We will continue to provide evidence-based resources on our website and incorporate feedback on content or additional needs.
- Information for GPs to give to people living with Paget's and their families/carers will continue to be available, with an enhanced priority in this area to foster best practices and raise standards.

Objective

4

Support Research into Paget's disease

Rationale

Better understanding, treatment, prevention, improved quality of life and, one day, a cure, requires high-quality research. The Paget's Association leads the way in supporting pioneering research that improves outcomes for people with Paget's disease.

How we will support research

■ In recognition of the Paget's disease research community in supporting the Association's goals throughout the past 50 years, for 2023 we launched our 50th Anniversary Research Awards, a new flexible funding scheme covering three areas and encouraging collaborative (multi-centre) research.

1. Pump-priming research e.g., pilot studies and/or defined pieces of experimental work that lead to clear opportunities to lever additional external funding
2. Educational activities and programmes that raise awareness about Paget's disease to health professionals and/or the broader public (the Winifred Ditchfield Award)
3. Capacity building in Paget's research, through flexible support for current or new postgraduate projects, or through undergraduate-led research projects e.g. student bursaries

Objective

5

Ensure continued good governance

Rationale

As a registered charity, the Paget's Association has always met its legal and moral obligations.

As legislation and the financial situation change it is important for the Association to be adaptable and flexible in ensuring we continue to demonstrate good governance.

How we will ensure continuing good governance

- We will focus on robust financial management on a daily basis, ensuring sufficient reserves are held while targeting expenditure to areas with maximum benefit for people with Paget's disease.
- We intend to create new income streams and continue to inspire legacies, particularly with the increased use of social media to encourage donations.
- As a charity, we will consider establishing the Paget's Association as a Charitable Incorporated Organisation (CIO) to align with current practice and provide additional benefits.
- Ongoing review and refinement of our policies across all areas will take place to ensure they are fit for purpose.
- We will continue to demonstrate accountability through regular correspondence/meetings with all stakeholders.

Contact us

Contact us if you would like to discuss this strategy

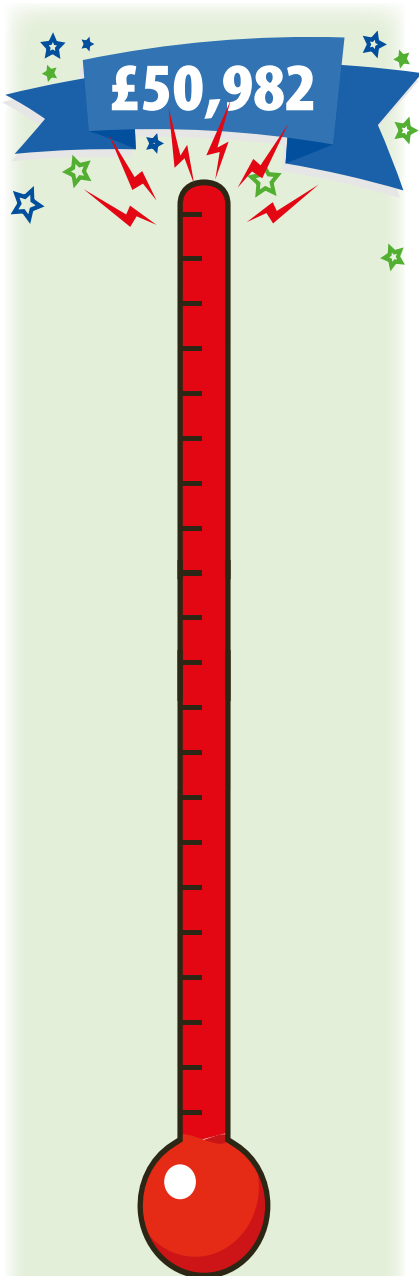
membership@paget.org.uk

0161 799 4646

www.paget.org.uk



50th Anniversary fundraising campaign



Thank you for making a difference!

Thank you to all those who have already donated, sponsored a challenge, or raised funds!

Wow!

Thank you to everyone who has raised funds or donated to our 50th Anniversary fundraising campaign. Last year we set out to raise £50,000 by December 2023 and we are absolutely delighted that we have exceeded this with a current total of £50,982. Your generosity is sincerely appreciated. Thank you!

Help us do more! Here's how to contribute

There are a number of ways you can donate or pay in funds you have raised. Simply get in touch for details or use the 'Donate' facility on our website.

Get in Touch

www.paget.org.uk

Call **0161 799 4646**

Email membership@paget.org.uk

New website coming soon!

In the coming months we will be launching a new website. Having a strong digital presence is crucial for the Paget's Association to be able to reach and help more people and part of this presence is a new, attractive and more intuitive website. Before embarking on this rebuild, we sought the opinions of members, the Association's Focus Group, clinicians and researchers. We would particularly like to thank members Mr Graham Dixon and Mr Alan Martin for their insights as to what they require most from our website.

Our new website will remain a powerhouse of information and aid our continued mission to raise awareness of Paget's disease and to provide support for people living with the condition and their families and carers.

This investment in the website will not only help us keep pace with the ever-changing digital world but it has also been built to be as energy efficient as possible. The pages load faster, are more accessible, deliver a better user experience and make our website easier to find. It is secure, accessible, scalable and hosted by a supplier whose data centre exclusively uses renewable energy.

Do take time to explore the information, stories and more. We would love to hear your feedback.

The Paget's Association's 50th Anniversary

Thank you to all those who attended any of our 50th Anniversary events in April at The Lowry, Salford Quays, Greater Manchester. The following provides an overview of the two days.

An opportunity to meet experts in Salford

Those affected by Paget's disease, their families, Trustees and friends gathered in Salford, for our Paget's Information Event. In celebration of the Association's 50th year, 50 sunflowers adorned the venue. These were lovingly made by member Marjorie Charnock from Leigh on Sea. Diana Wilkinson, Specialist Paget's Nurse for the Association, summarises the afternoon below.

50 years of help and support

I was delighted to Chair the Paget's Information Event in celebration of the Paget's Association's 50th Anniversary. It seemed fitting to open the event with a brief introduction to the charity's humble beginnings. Prior to the birth of the Association in 1973, Alf Stansfield was an inspector on the buses in Greater Manchester. He suffered from pain for many years and was treated for all kinds of things such as fibromyalgia. Eventually, the source of his pain was found to be Paget's disease. He wasn't the first, nor the last, to receive this diagnosis following a long period of suffering and misdiagnoses, but he was the first with a wife like Ann Stansfield.



Made by Marjorie Charnock, 50 sunflowers decorated the venue

She promised him she would do everything she could to find out as much about the condition as possible.

Ann kept that promise. Not only did she help Alf but she supported many others as well. She wrote to hospitals and universities all over the world to obtain information and raise awareness of the condition.

It was Ann who founded our charity

in 1973 when Dr Allan St John Dixon helped her convert what she was already doing into a charity. Dr Dixon was also the first Chairman and later Honorary President. Ann and her supporters raised money to fund the Association, including research into Paget's disease. As a result many people were helped and the charity went from strength to strength. In 1983 Ann's work was recognised with an MBE.



Members, Graham and Janet Dixon, with a display of photographs from 50 years of the Paget's Association, created by Sue Clegg and Jen Woodworth

Now, 50 years later, our aims are the same as they were then, to provide information and support to those who need it, to fund and encourage research and to raise awareness of the disease. I thanked all those present who had supported the Association in any way and I want to reiterate that to those of you reading this who have ever donated your time and/or funds, because

the charity simply couldn't have survived without you.

Clearly, most people affected by a particular condition simply don't have the opportunity to hear directly from international experts and ask questions. This event was very special as we had speakers not only from the UK but also from Canada and New Zealand.



Diana explained how the Association was founded

Insights from Canada into Environmental Factors



Dr Laetitia Michou

Dr Laetitia Michou from Canada, a rheumatologist caring for those with Paget's disease and an Associate Professor in the Department of Medicine at Laval University, Quebec, discussed genetics and the environment in relation to Paget's disease as both have been implicated in how the disease develops. There are known genetic factors associated with the development of the condition and these have been well-documented, as has the decline in the incidence and severity of Paget's disease.

This decline may be related to changes in environmental factors. Many potential contributors have been suggested and studied, such as viruses, pollution, food and contact with animals (pets and livestock). Dr Michou's research showed that in French-Canadian families, 43% of those with Paget's disease were former or current tobacco users versus 18% of relatives without this condition and the condition was associated with wood-fired heating in childhood/adolescence.

Diagnosis – past, present and future

Professor Stuart Ralston, Chair of the Paget's Association and a rheumatologist and researcher in Edinburgh, discussed diagnosis – past, present and future. He explained that diagnosis usually consisted of an assessment of symptoms such as pain, observing for signs of the condition e.g. bone enlargement and investigations such as blood tests, x-ray and a bone scan. Early diagnosis in those who are genetically susceptible to Paget's disease was considered in the Zoledronate in the Prevention of Paget's (ZiPP) study, which some of you may have taken part in. The study found that genetic testing

and targeted treatment can detect and reduce progression of early Paget's disease. The treatment was well-tolerated and the effects long-lasting. Insights from the ongoing research may provide information on who should be targeted for early treatment.



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Insights from the ongoing research may provide information on who should be targeted for early treatment

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Continued overleaf



Mr Nav Makaram

Orthopaedic surgery in Paget's

Mr Nav Makaram from Edinburgh spoke about orthopaedic surgery. He began by stating that around 8% of patients with Paget's disease require orthopaedic surgery e.g. to repair a fracture, straighten a bone (osteotomy) or to replace a joint. The most common operation is total joint (hip or knee) replacement. He explained that Paget's likely exacerbates arthritic changes in the joint due to structurally weakened and abnormally shaped bone, altering the mechanical forces through the joint. After explaining the surgical procedures in more detail he summarised the following points.

- Orthopaedic surgery still has an important role in Paget's disease despite improvements in medical management
- The most common surgical treatments for Paget's include joint replacement, osteotomy and fracture fixation
- Outcomes of joint replacement in Paget's are successful and comparable with that of the general population, but there is some evidence that there is an increased risk of some complications
- Careful preoperative planning with the individual with Paget's disease and the team caring for them can ensure optimal outcomes
- More research is needed on the outcomes of fracture repair and total joint replacement in those with Paget's

Benefits and risks of medical treatment

Professor Ian Reid is an endocrinologist and researcher at the University of Auckland, New Zealand. He has worked extensively in the development of bisphosphonates to treat Paget's and has widely researched calcium and vitamin D. He discussed the benefits and risks of medical treatment, explaining that research shows that when Paget's disease is treated with a bisphosphonate, bone pain is relieved, quality of life improved and bone cells behave more normally. Thus, disease progression is slowed. Studies have not assessed whether important things such as fractures and the need for joint replacement surgery are diminished but since disease progression is reduced



Professor Ian Reid with Trustee Amanda Sherwood

by potent bisphosphonates, it is possible that disease complications may be prevented.

Zoledronic acid (a bisphosphonate given by a drip into the bloodstream) is the main treatment for Paget's disease and its most frequent side effect is a flu-like reaction known as the Acute Phase Response (APR). This is an inflammatory reaction often involving fever, musculoskeletal pain, headache, and nausea. Professor Reid highlighted

recent research that had investigated the efficacy of a three-day course of the steroid dexamethasone (4 mg daily) to reduce the incidence of APR. The study demonstrated that it substantially reduced APR following an infusion of zoledronic acid.

An excellent opportunity

The speakers gave us lots to think about and answered many questions. If you were able to attend, thank you for coming and if not, I hope you will consider coming to one of our events in the future. As well as being very informative, they provide a good opportunity to get together with others in a similar position and make new friends. I hope to see some of you at our October event in Stafford.

Diana

An International Paget's Symposium

An International Paget's Symposium took place in Salford, Greater Manchester, as part of the Paget's Association's 50th Anniversary events. This two-day event for researchers, clinicians, educators and students gave them opportunity to present and discuss their research in great detail. Experts from all over the world showed their enthusiasm for improving patient care and stimulating innovative research.

The Symposium was approved by the Federation of the Royal Colleges of Physicians (UK) for Continuing Professional Development credits which meant that attending physicians could show that they were engaged in an ongoing process of improving their skills and competencies in the field of Paget's disease.

Setting the scene with personal experience

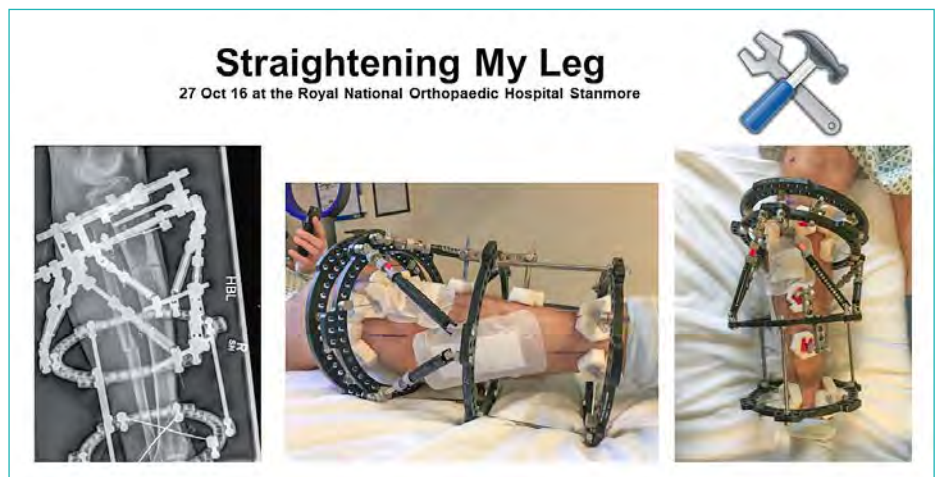
We know that those affected by Paget's disease want the health professionals they come into contact with to be well-educated regarding all aspects of the condition. It was appropriate, therefore, that member of the Association, Simon Leigh from Dorset, set the scene from the start as he discussed his experience of living with the condition.

Simon described how he was diagnosed aged 55 with Paget's in his right tibia. He said that, prior to treatment, it was an awful disease to live with. It was alarming, he had terrible pain and difficulty walking. Thankfully he had successful treatment with an infusion of zoledronic acid and then opted to have his bowed leg surgically straightened. This was a big decision and a long process of about six months. It involved breaking the bones (osteotomy) of his lower leg (tibia and fibula) and having lots of holes drilled in the bone to fit a frame to his leg. Careful daily adjustments of the frame allowed his bones to heal and his



Above: Simon gets the Symposium off to a good start by explaining his personal experience of Paget's disease

Below: one of his slides showing the Taylor Spatial Frame used in the process of straightening his leg



leg to straighten. The surgery was a success. Simon was pleased with the outcome and that the disease had been in remission since 2016 without any further infusions.

The 44 speakers who followed Simon covered everything from an ancient form of the disease and genetics to artificial intelligence and the future of diagnosis and treatment.

Thank you

We would like to thank the speakers and delegates from across the globe, including India, New Zealand, Canada, the US and Europe, for their interest in Paget's disease and for making our 50th Anniversary Symposium extra special.

A celebration

A Gala Evening took place for the Paget's Association's 50th Anniversary. It was a magnificent celebration and it was fitting that it took place in Greater Manchester, the birthplace of the charity.

Opening the celebrations, Patron of the Paget's Association, Sir Henry Paget, explained that Paget's disease was originally described in 1887 by his great, great, grandfather, Sir James Paget. He highlighted how the charity was established 50 years ago by Mrs Ann Stansfield, whose husband suffered from the condition. Ann's motivation for starting the charity was the fact that she found it very difficult to find out anything about the disease which had affected her husband so badly.

Professor Graham Russell has been Honorary President of the Association for the past 12 years and Sir Henry presented him with a medal and gift, for his service and in recognition of the key role he played in the development of bisphosphonates which are now the treatment of choice for Paget's disease.



Sir Henry Paget asked everyone to join him in a toast to the Paget's Association



Sir Henry Paget and Professor Graham Russell



Members of staff enjoy the evening: Sue Clegg (left) and Jen Woodworth (right)



Patron Recardo Patrick gave a live performance



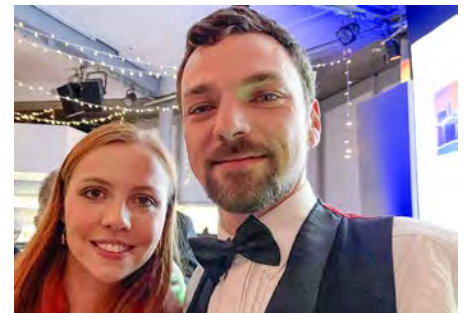
Recardo with member Deborah Valentine



Member of staff, Diana Wilkinson with Master of Ceremonies, Phil Colbert



Former Vice-Chair of the Association Dr Stephen Tuck and his wife Dr Julie Walker



Daphne and Johnnie Dingwell, Sir Henry Paget's daughter and son-in-law



Journal news



For this edition, Professor Rob Layfield, Chair of the Association's Research Subcommittee, has chosen two recently published papers. The first discusses an incidental finding of Paget's disease in Poland and the second looks at the decline in the clinical severity of Paget's in Quebec, Canada. Our Specialist Nurse, Diana Wilkinson, summarises both here.

An incidental finding of Paget's disease

This paper from a clinical team in Poland illustrates an incidental finding of Paget's disease. It is not unusual for the condition to be diagnosed when investigations are performed for another reason. This case provides an example of this but also shows that the clinicians caring for the man did the right thing in referring him to rheumatology colleagues, something that we at the Paget's Association know does not always happen.

Living donor kidney transplantation is often the treatment of choice for those with end-stage renal disease. The welfare and care of the living donor is paramount and they must meet health criteria included in local and international guidelines. A thorough assessment and medical evaluation of the living-donor

candidate is very important. This can reveal previously undiagnosed diseases. Early detection of disease may benefit the donor and it could mean that they have to withdraw from the transplant process. The team in Poland presented a case of a living kidney donor who had to withdraw due to previously undiagnosed Paget's disease.

A 54-year-old man was a potential kidney donor for his daughter. He declared good health with no complaints other than occasional back pain. He underwent several investigations including a blood test that revealed that he had a higher than normal level of alkaline phosphatase (ALP) at 199 U/L (normal range 40–129 U/L), which is often raised in Paget's disease. In addition, the CT scan showed an abnormality of the fourth lumbar vertebra (L4). A chronic fracture was initially suspected but a subsequent MRI suggested a Pagetic lesion and therefore a diagnosis of Paget's disease.

To evaluate whether other bones were affected a nuclear bone scan (scintigraphy) was carried out. This confirmed Paget's disease was only

in one bone (monostotic disease), the 4th lumbar vertebra (L4) and it showed that no other bones were affected (so not polyostotic disease).

The man was also evaluated for osteoporosis and following all the investigations was withdrawn from the living kidney donor program. The authors do not discuss their reasons for withdrawal in this paper as they had previously published a detailed discussion of this. The individual was referred to the rheumatology department for further evaluation and went on to be successfully treated for Paget's disease with risedronate tablets.

REFERENCE

Jędrzejuk D, Poznański P, Szewczyk P, Mazanowska O, Bolanowski M, Krajewska M, Kamińska D. Newly Diagnosed Monostotic Paget's Disease of Bone during Living Kidney Donor Candidate Evaluation. *Biomedicines*. 2023 Jan 29;11(2):401.



Full text

The full text is available online by scanning the QR code with a smartphone or

searching for the above reference.

Decline in clinical severity of Paget's in Canada

The authors of this paper explained that both European and Australian studies have reported a decrease in the prevalence, incidence and clinical severity of Paget's disease. As there were no studies on the current clinical characteristics of the condition in Quebec, Canada, the team there compared unrelated people with Paget's diagnosed after the year 2000, to a historical group diagnosed before 2000.

Information was collected from electronic medical records of those with Paget's disease known to Laval University Hospital in Quebec. For the historical group, the same data was collected from the research files of participants in their research program. Individuals were excluded if they were known to have a relative with the condition.

The researchers found the following:

- Among the 195 people in the contemporary group (after 2000) 53.3% were men, 60.5% had one bone involved (monostotic), and 14.2% were symptomatic at diagnosis.
- In comparison to the historical group (before 2000) of 173, people in the contemporary group were older at diagnosis (68.7 ± 10.7 vs. 58.5 ± 10.1 ; $p < 0.0001$) and had less family history of Paget's disease (13.8 % vs. 33.6 %; $p = 0.0024$).
- The contemporary group also had lower serum total alkaline phosphatase levels at diagnosis (118.0 (85.0–184.0) vs. 184.0 (115.0–312.0); $p = 0.0006$), a lower number

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In contrast to most studies of the clinical presentation of Paget's, a significant decrease in bone deformity was found over time
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of bones involved (1.0 (1.0–3.0) vs. 2.0 (1.0–5.0); $p < 0.0001$), fewer fractures in the Pagetic bone (6.7 % vs. 36.7 %; $p = 0.0078$) and fewer bone deformities (13.0 % vs. 54.0 %; $p < 0.0001$).

- There was no significant difference for Pagetic bone pain (52.0 % vs. 52.6 %; $p = 1.0000$), percentage of patients who had orthopaedic surgery related to complications of Paget's disease (8.8 % vs. 28.6 %; $p = 1.0000$), secondary osteoarthritis (43.0 % vs. 51.6 %; $p = 1.0000$), and hearing impairment (51.9 % vs. 61.1 %; $p = 0.1000$).

The authors of the paper noted that the results need to be treated with caution and only be generalised to other Caucasian populations of non-familial Paget's disease. Given the absence of any study on the clinical manifestations of Paget's in Eastern Quebec, these results allow physicians to look out for less severe

clinical presentations that could be more difficult to recognise.

In summary, this study showed the downward trend in the severity of Paget's disease in Eastern Quebec, with an older age at diagnosis, fewer affected bones (majority monostotic), fewer complications, and lower serum total alkaline phosphatase levels.

The findings are consistent with the results from Australia, New Zealand, Italy and partly consistent with studies from Spain which also noted a decline in clinical severity over recent decades. In contrast to most studies of the clinical presentation of Paget's, a significant decrease in bone deformity was found over time, although the number of people in this subgroup was small.

This research may encourage further studies in which we could gain a better understanding of the causes behind this trend.

REFERENCE

Gendron E, Bouchard F, Singbo N, Brown JP, Michou L. Decline in clinical severity of Paget's disease of bone: Comparison between a contemporary cohort and a historical cohort. *Bone*. 2023 May;170:116721. doi: 10.1016/j.bone.2023.116721. Epub 2023 Feb 27. PMID: 36858336.



Full text

The full text is available online by scanning the QR code with a smartphone or

searching for the above reference.

A tribute to Doreen

When we heard the sad news that Doreen Scott aged 87 had passed away in April, we knew that we had lost not only a loyal supporter but also a dear friend.

Doreen lived in Cleator Moor, Cumbria and was diagnosed with Paget's disease ten years after she first noticed symptoms. Following a blood test in 2010, she was told there was damage to her liver and was advised to stop drinking alcohol. As she had not had alcohol for many years she asked for a scan but despite her pain this was refused.

Doreen's legs, pelvis and head were painful, her left arm began to bend and by April 2011 she had reached rock bottom. She saw her GP again who looked back at her records and explained that the level of alkaline phosphatase (ALP) in her blood had gradually been increasing over a ten-year period. When the ALP is raised it quite often indicates a problem with the liver but finally at this point, Paget's disease was suspected and she was relieved to be referred to a consultant in Lancaster. The result of a bone scan confirmed extensive Paget's disease. She had treatment with zoledronic acid and whilst she felt quite poorly afterwards with flu-like side effects, her pain subsided. She was pain-free for some months before requiring further treatment.



Doreen (left) and Diana (right) at a support group meeting in 2013



Her consultant provided literature about the Paget's Association so she made contact and became a member, volunteer and friend. She found great comfort in the information and support she received. Writing for the Paget's News magazine in 2012 Doreen said, 'Get to know as much information about the condition as you can and absorb it. I truly believe that it helps take away the fear of the unknown. Involve your family, tell them about it so that they can understand and offer you moral support. Keep going and cope with the condition the best you can. Your life changes – accept and adapt. Realise that most people with a long-term condition can get very low but remember you are not on your own. Some days I miss being me! If you are not in a good place mentally, it will be difficult to deal with. The support and understanding of family, friends and the Association can help you through the difficult times.'

Keen to help others and with the support of our Specialist Nurse Diana Wilkinson, one of the things Doreen did was to try to start a support group in 2013, in Keswick, Cumbria. Unfortunately, the

meetings were not well attended and the group had to close. Diana commented, 'Doreen's battle with Paget's disease wasn't an easy one. I will always remember Doreen for being an incredible lady with a positive outlook, and someone who always wanted to help others. Our thoughts are with all her family and friends at this time.'

Doreen joined the Association's Support Network where she found mutual support and lifelong friends. In a previous magazine Doreen had commented, 'I have friends all over the world now – we help each other'. Hearing of her passing, Network member, Maria Coteanu, from Canada said, 'She became a very dear friend. I miss her a lot. We became close despite the distance. I am very fortunate to have known her and I wish I could have met her in person. Her memory will be with me for years to come.'



Legacies have allowed the Association to reach its 50th year

We are so grateful for every gift left to the Association in a will. Certainly, without such legacies the Paget's Association would not have been able to reach its 50th year this year.

Remembering family and friends on birthdays and anniversaries

Thank you to all those who have chosen to remember someone by donating to the Association in memory of a loved one on birthdays or anniversaries. Your kindness is appreciated.

*In celebration and
remembrance*

of


Doreen Scott

Percy Nicholson

Reginald Kay

*We are grateful to their
families and friends for
their thoughtfulness
and lasting gifts*





Information and support services provided by the Paget's Association

Paget's Buddies

If you would like to talk to someone else who has Paget's disease, simply get in touch

Paget's Nurse Helpline

Contact us for support, information, advice or simply a listening ear

Email: helpline@paget.org.uk

Telephone: **0161 799 4646**

Mobile: **07713568197**

Paget's information videos

Watch on YouTube a series of interviews by Professor Stuart Ralston about personal experiences, treatment and research

Search

YouTube for

@PagetsAssociation

Paget's Network

Connect with several other members by phone, letter, email or however you would like to communicate

Request a Support Network form

Information

Our latest information booklets can be downloaded from our website or sent to you by email or post

Coffee, Cake & Chat – Crystal Peaks

Join this small group of members, family and friends, and our nurse, Diana, for coffee, cake and a chat, plus support and information, in the Crystal Peaks shopping centre – southeast of Sheffield (reasonable refreshments included)

Contact us for details

Virtual Paget's Support Groups

Meet others affected by Paget's disease at one of our virtual support groups. For more information or to take part, please email membership@paget.org.uk or register on our website

Facebook support group

To join, please scan the QR code with a smartphone or visit

<https://www.facebook.com/groups/pagetsdiseaseofbone>



Meet the team at the Paget's Association

Honorary President



Professor Graham Russell

Involved in research at both

the Botnar Research Centre, Oxford and the Mellanby Centre for Bone Research, Sheffield, Graham played a key role in the discovery and development of bisphosphonates for the treatment of bone disorders.

Patrons



Sir Henry Paget

Sir Henry is the great-great grandson of Sir James

Paget, whose name was given to Paget's disease.



Mrs Joyce Cupitt

Joyce served as a Trustee for many years. Her late

husband had Paget's disease.



Mr Recardo Patrick

Recardo is an entertainer and businessman

who rose to fame as lead singer with the band, Sweet Sensation. He has Paget's disease.

Employees



Mrs Diana Wilkinson



Miss Jen Woodworth

Board of Trustees



Chair of the Board – Professor Stuart Ralston

Chair of the Paget's Association, Stuart is a Rheumatologist, based at the Western General Hospital, Edinburgh. He has researched widely on the role of both genetic and environmental factors in Paget's disease and has led several large clinical trials investigating the best methods of treatment for Paget's.



Vice-Chair – Professor Rob Layfield

Rob is a Professor at the University of Nottingham. He researches the protein that was found to carry mutations in some cases of Paget's disease.



Mrs Eve Berry

With many years of experience in the healthcare sector, Eve lives in London and is a Chartered Accountant, currently working in the drug discovery industry.



Mrs Kely Burman

A retired nurse and midwife living in Orsett, Kely has not only cared for those with Paget's disease, but her mother also had the condition.



Dr Sheelagh Farrow

Sheelagh lives in Surrey and, prior to retirement, was Managing Director of International Medical Press, a provider of independent medical education.



Mr Alan Janes

Alan is a retired Company Director who has Paget's disease, and is a volunteer within his local community in Oxford.



Dr Catherine Nairn

A General Practitioner, Catherine developed an interest in Paget's disease while working at the Western General Hospital, in Edinburgh.



Dr Faiz Rahman

Faiz is a Consultant in Metabolic Medicine and Chemical Pathology, at the University Hospitals of Leicester, where he is involved in caring for those with Paget's disease.



Mrs Amanda Sherwood

Amanda lives in Bristol and is now retired. She has experience in working for societies and teaching organisations which specialise in the field of bone and related topics.



Professor Mark Wilkinson

An Orthopaedic Surgeon in the Metabolic Bone Unit of the University of Sheffield, Mark has both an academic and clinical interest in Paget's disease.



136 years since Paget's disease was first described in 1887 by Sir James Paget. Sir Henry Paget, his great great grandson, proposed a toast to the Paget's Association at the 50th Anniversary Gala Evening



50 years since Ann Stansfield founded the Paget's Association in 1973 with support from Dr Allan St John Dixon. In 1983 Ann received an MBE



45 people from around the globe gave presentations at the International Paget's Symposium at The Lowry, Salford, Greater Manchester



4 new Paget's Association Centres of Excellence announced in 2023, adding to our growing list of centres for excellence in care and research



5 years since International Paget's Awareness day was introduced in 2019. It now takes place on 11 January each year



£9,000

committed in 2023 to a new educational project that will also raise awareness of Paget's disease



£50,982

raised by members, supporters, Trustees and staff for the 50th Anniversary Fundraising Campaign
Photo: Diana Wilkinson's Wing Walk

33 people attended the 50th Anniversary patient and family Information Event in Salford and had the opportunity to ask questions of experts, who were not only from the UK but also Canada and New Zealand



£366,112

committed to current research projects which will increase our knowledge of Paget's disease and ultimately improve care for patients

